Challenge TB – Core Measurement Stigma

Year 2

Quarterly Monitoring Report

January-March 2016

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1. Quarterly Overview

Country	Core project measurement: Stigma
Lead Partner	KNCV
Other partners	MSH
Workplan timeframe	July 2015 – September 2016
Reporting period	January- March 2016

Summary progress report:

This is the second quarter of the Core Measurement- Stigma project implementation. TB stigma measurement and reduction continue to be both engaging and challenging issues for Challenge TB and the wider TB community. In February, an article in Development Policy Review rated the question of how to reduce discriminatory behavior by health care workers as one of the top 100 most important development questions. Unprecedented interest in the stigma project from WHO, GFATM, Stop TB Partnership, and partners working in other stigmatized areas continues, with numerous stakeholders offering ideas, methods, recommendations, and names to add to the expert meeting. CTB sees this interest as an opportunity to leverage additional resources to make substantial progress on policy and practices that reduce stigma and help increase the effectiveness of TB case-finding and treatment support interventions.

The need for a validated TB stigma scale was reiterated during the recent Global Fund Human Rights consultation. The Gender and Human Rights team of GFATM is particularly keen to invest in scientifically validated tools and strategies. The TERG will evaluate the Gender and Human Rights strategy of GFATM this year. WHO and other stakeholders have suggested that funds may be available to field test TB stigma tools and guidance when they have been completed and validated.

The core project made noteworthy progress on all activities this quarter. Of significance are:

1. Completion of preliminary analysis of the anticipated stigma surveys
2. Completion of data extraction for the systematic literature review analysis
3. Engagement of a stigma scales expert to guide the analysis of the robustness of TB scales
4. Achieving consensus on the design and scope of the TB stigma expert meetings
5. Identification of appropriate partners to conduct the validation of new scales, leveraging funds from other donors

The core project is on track for reaching key milestones. April will be critical as key draft deliverables need to be shared before the stakeholder meeting in order for the gathering to be efficient – reaching consensus on technical issues in a brief window.

The pressure to produce useful guidance has been heightened in recent weeks. The draft Global Fund Strategic Plan 2017-2022 discussed in April promises a GFATM pivot on stigma "moving from rhetoric to investing" (p.21). The document suggests that stigma can be addressed through a rights-based approach focused on "people living with or affected by diseases" and that "practical programs" already exist. Whether this is aspirational or actual, it is true that stigma functions as a barrier to care in our field and there is an appetite for addressing it in a practical, evidence-based and cost effective manner.

Technical:
There are seven aspects of the TB STIGMA core project, and technical progress in each area is summarized in order.

1. Prevalence Survey Review
2. Assess distribution and correlates of anticipated stigma in the general population
3. Assess the distribution and correlates of enacted stigma in health care settings
4. Assess robustness of existing TB stigma measures
5. Systematic literature review of stigma reduction strategies (Map what works)
6. Convene expert meetings
7. Prepare protocol for piloting and Baseline Stigma Measurement

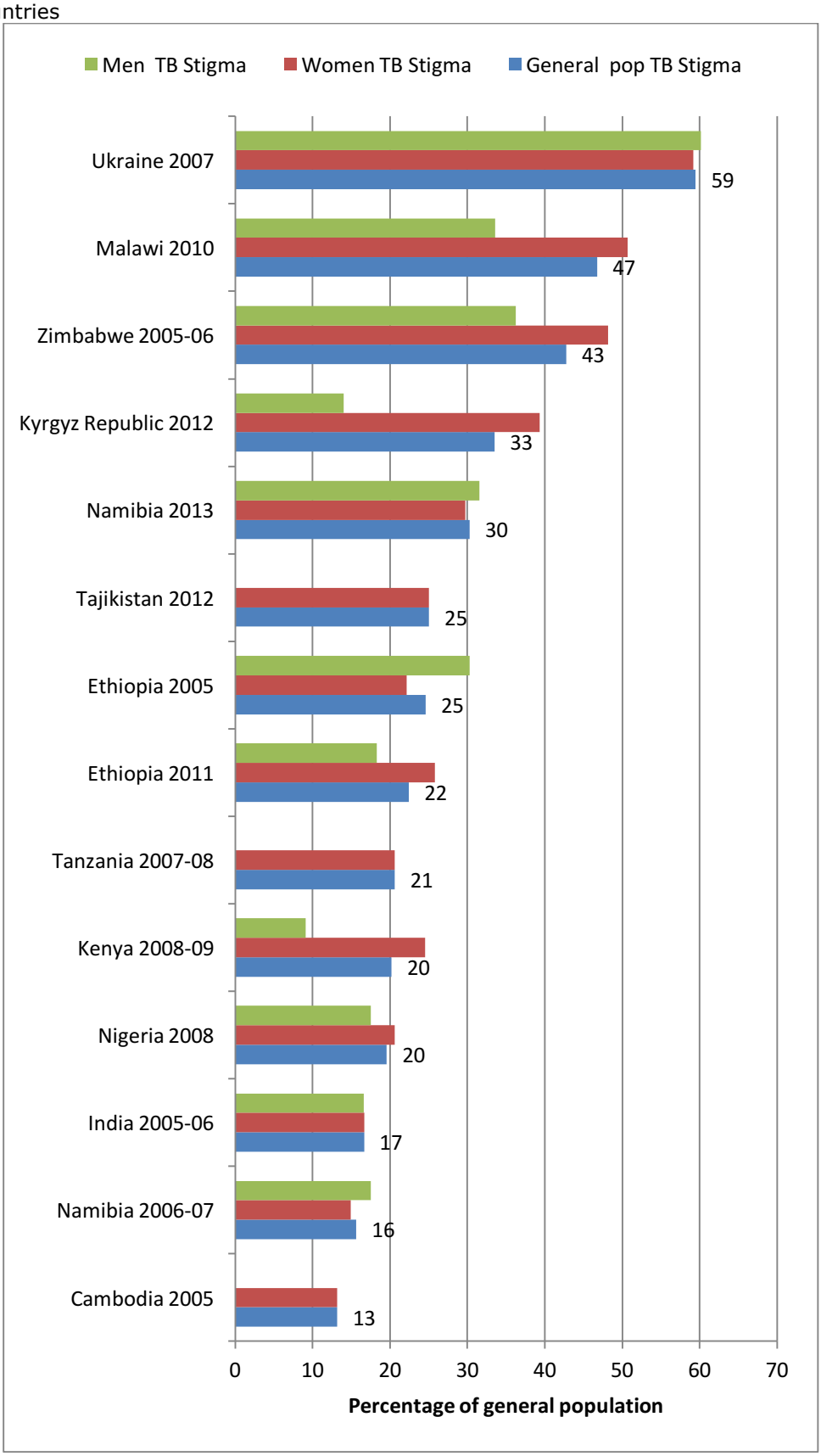
1. Prevalence Survey Review

In 2015, Bill and Melinda Gates Foundation and USAID undertook an analysis of the role of prevalence surveys in TB control. KNCV's Eveline Klinkenberg provided expert support to this endeavor, having participated in multiple prevalence survey efforts. During this reporting period the global prevalence assessment report was completed and formally submitted to USAID on March 17th. The report will serve as a background document and has been presented during the Global Task Force meeting in Glion, mid-April. Further, in March follow up work started on one of the recommendations of this assessment. This work involves the creation of a Data Monitoring Board to bring these surveys more in line with good clinical practice.

2. Assess distribution and correlates of anticipated stigma in the general population

During this reporting period (Jan-Mar, 2016), Lisa Redwood prepared datasets for KIT. Data on covariate factors to associate with TB stigma are collated from various open source online data repositories (e.g. WHO data). KIT appended and quality controlled all 19 survey data sets and ecological data from 44 countries. The preliminary analysis indicated a high degree of variation within and among countries, and few sociodemographic predictors. CTB countries with a very high general population stigma level include Ukraine, Malawi, Zimbabwe, and Namibia. Namibia is particularly interesting because stigma has apparently really increased in the 2007 to 2013 period. This stands in sharp contrast with Ethiopia, where it has remained virtually unchanged. (Please see Figure 1.)

Figure 1: Attitudes Toward Family Member TB disease Disclosure in DHS Survey Data for CTB Countries

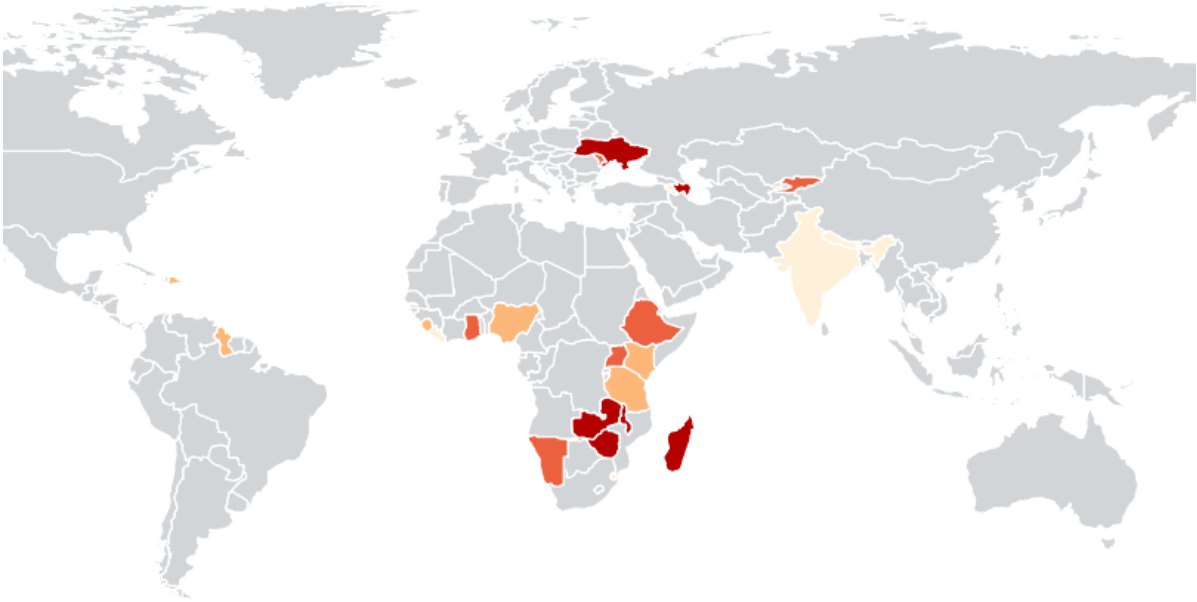


The preliminary predictors of TB non-disclosure (as a proxy measure for anticipated stigma) are: gender (women would disclose less often), religion (Atheists and Christians would disclose less often). The most interesting preliminary finding is that the greater the proportion of people aware

of the airborne route of TB transmission, the lower the proportion that would disclose that a family member has TB. That has important (and possibly counterintuitive) implications for anti-stigma campaigns that focus on increasing understanding of TB etiology to decrease stigma.

KIT has also addressed the question of whether TB stigmas are compound stigmas. In other words: Do TB stigmas elide with stigmas of poverty, incarceration, substance use, and HIV? If yes, how then do we measure it? TB non-disclosure is strongly associated with negative attitudes towards HIV at the country level, but at the individual level there is much more variation that we are exploring. For example, higher SES people tend to have less HIV stigma, but more TB stigma –suggesting that TB disease non-disclosure may have some links to class and social rank.

Figure 1: Nineteen Countries included in the DHS TB Disease Non-disclosure Analysis



An Ecological Analysis is underway of 44 countries' DHS datasets. National estimates of TB stigma are calculated from DHS survey data carried out between 2005-2014, using non-disclosure of a family member having TB as a proxy of anticipated TB stigma. Generalized linear models using inverse population weights were fitted to the data. Uni-and multivariate model results will be presented and interdependencies between anticipated TB stigma and social and health related factors will be discussed. Between country variations in these associations (and the implication for standardized measures) will be a topic of discussion at the expert meeting.

A nested sub-study of the DHS general population stigma work package is the question of the validity (or not) of the disclosure question as a proxy measure of TB stigma. Hypothetical secrecy questions are often referred to as "disclosure questions" in the literature. There is a robust debate about whether disclosure of HIV status is a proxy for anticipated HIV stigma or not. This debate has yet to occur for TB stigma. Charlotte Colvin and Ellen Mitchell have been working on an analysis of a dataset from clients with chronic cough in 5 outpatient settings in San Pedro Sula Honduras from 2005 to try to tease apart the relationship (if any) between attitudes toward disclosure of TB disease and classical TB stigma. A seven-item TB stigma scale has been validated and an analysis plan has been drafted.

There are only two Items on disease disclosure in the Honduras dataset. These items are particularly useful because they state the underlying rationale for disclosure, making them more interpretable than the DHS questions.

9. It is better not to hide that you have TB, so that you can benefit from the support of friends and family.

10. A person with TB should tell others only when s/he becomes very sick and has no other choice.

There are eight items in the Likert scale designed by Colvin in 2005 for measurement of TB stigma. Three stigma items are posed indirectly (#3-7) reflecting prevailing norms, negative stereotypes and fear However, two are direct (#8 and #11) –referring to personal behavior. These latter items are more likely to be contaminated by social desirability bias or confounded by loyalty to family and friends, a core value in many cultures.

- 3. People with TB are usually poor.
- 4. People with TB usually live in an unclean house.
- 5. People with TB usually have little education.
- 6. If a friend of mine had TB, people would avoid him/her.
- 7. If a friend of mine had TB, s/he would probably lose his/her job.
- 8. If I knew a friend of mine had TB, I would no longer associate with him/her.
- 11. I would be willing to care for a relative with TB in my house.
- 17. If a friend of mine was diagnosed with TB, I would worry that s/he also has HIV/AIDS.

The methods section and preliminary results are drafted. Not surprisingly, the direct questions about family do not contribute to the construct validity of the scale and are dropped in the final scale. Anticipated stigma is better measured without reference to how people would treat their family.

Some additional exploratory factor analysis is needed for the scale before the results are presented, but the key question: "Does a single hypothetical TB disease disclosure question measure TB stigma?" seems to be answerable., One disclosure question is NOT a simple proxy for a validated measure of TB stigma, but since they do appear to be highly correlated, the DHS disclosure question may be used as a benchmark of TB stigma.

The practical implication of this initial finding from the Honduras study data set is that we may be able to make use of the DHS surveys that have been conducted in 44 countries to map TB stigma as an indicator. While it is not an ideal indicator, given that it is freely available and highly correlated, we may consider to use it as part of the M&E system of Challenge TB when stigma reduction efforts are undertaken targeting the general population.

3. Assess the distribution and correlates of enacted stigma in health care settings

KNCV provided the outstanding Service Provision Assessment (SPA) datasets to KIT, which enabled a preliminary statistical analysis plan to be developed. Discussions were held to further define the study endpoints. The emphasis is to examine the variation in the presence of discrimination in health facilities. KIT is progressing on the analyses with preliminary data analyses expected the first week of May. This SOW is slightly behind schedule but we've shared our concerns with the sub-contractor and we will continue to monitor progress on a regular basis to ensure timely completion. This analysis is a lower priority than the rest because the stigma measured is ambiguously defined in the survey. However, we are hopeful that this will tell us more about variation in stigma perception by different types of health care workers in the same institution.

Critical to the issue of stigma in health care settings in the potential conflation of stigma (irrational fear of moral contamination) with social distancing due to rational fear of nosocomial transmission. The importance of dissecting these two distinct issues is paramount, but the best means to do it are unclear. Discussion with Ed Nardell (Harvard), Ginny Lipke (CDC), Tom Yates (LSTMH), Max Meis (KNCV) and others suggest that there are few researchers working on this issue outside of South Africa, and even fewer implementers. Nevertheless we consider this to be a very important dilemma to address in the context of the expert meeting and in CTB interventions.

4. Assess robustness of existing TB stigma measures

KNCV conducted a global literature search to identify all TB stigma scales. The resulting search has identified 29 different TB and TB/HIV scales, most focused upon health care workers and TB patients, with only the Van Rie scale validated for the general population (see matrix).

A dropbox site was created with all study materials and data on each scale were abstracted into a database using a template designed by University of Vanderbilt epidemiologist Dr. Aaron Kipp, Epidemiologist at U. Vanderbilt (who validated the Van Rie TB Stigma scale as part of a PhD at UNC).

TB Stigma Matrix

	General community	TB patients	Health care workers
Anticipated stigma	1	2	3
Internalized stigma		4	6
Experienced stigma		6	7

5. Systematic literature review of stigma reduction strategies (Map what works)

The review protocol was finalized and registered in PROSPERO (http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016036670).

University of Antwerp graduate student Nina Sommerland and Ellen Mitchell (KNCV) conducted the literature searches in EMBASE, PUBMED, CINHAL, WHO LILACS, and grey literature sites (CDC, TSRU, etc.). The project team conducted a 100% verification of the first screening by U. Antwerp, and following a secondary screening of full texts, only seven studies were eligible for final inclusion.

- Balogun MS, A.; Meloni, S. T.; Odukoya, O.; Onajole, A.; Longe-Peters, O.; Ogunsola, F.; Kanki, P. J. Trained community volunteers improve tuberculosis knowledge and attitudes among adults in a periurban community in southwest Nigeria. American Journal of Tropical Medicine & Hygiene. 2015;92(3):625-32
- Wu PSC, P.; Chang, N. T.; Sun, W. J.; Kuo, H. S. Assessment of changes in knowledge and stigmatization following tuberculosis training workshops in taiwan. Journal of the Formosan Medical Association. 2009;108(5):377-85
- Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through "TB clubs" in rural North Ethiopia. Soc Sci Med. 2003;56(10):2009-18
- R. P. C. Croft, R. A. Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh
- Macq JS, A.; Martinez, G.; Martiny, P. Tackling tuberculosis patients' internalized social stigma through patient centred care: an intervention study in rural Nicaragua. BMC Public Health. 2008;8:154.
- Acha JS, A.; Guerra, D.; Chalco, K.; Castillo, H.; Palacios, E. Psychosocial support groups for patients with multidrug-resistant tuberculosis: five years of experience. Global Public Health. 2007;2(4):404-17
- Chalco KRW, D. Y. Ba; Mestanza, L. Rn; Munoz, M. Rn; Llaro, K. Rn; Guerra, D. Rn; Palacios, E. Rn; Furin, J. M. D. PhD; Shin, S. Md Mph; Sapag, R. Md Mph. Nurses as providers of emotional support to patients with MDR-TB. International Nursing Review. 2006;53(4):253-60

This is far fewer than anticipated. Moreover most of them are older and heterogeneous. Three are among TB patients, two among health care workers, and two targeted the general population. These data have been abstracted, graded, and a the report is being prepared and we expect a first draft in the first week of May.

The immediate implication of the lack of well-measured intervention studies identified in this review is that it will be challenging to provide guidance to CTB countries on what works to reduce stigma in the short term.

Recognition of the potential for limited evidence on effective interventions to reduce TB stigma was impetus for organizing an additional one-day meeting to leverage knowledge from other stigmatized fields on effective strategies that might be adapted to TB.

6. Convene expert meetings

An unexpectedly positive response to the two meetings has resulted in a high level of participation by academics, donors, partners and stakeholders who are leveraging their own funds to attend. There is interest from WHO to have a validated TB stigma index that can be included as part of the measurement framework for the END TB strategy. There is interest from GFATM to have a TB stigma index to use as part of their KPI for their investments in anti-discrimination efforts.

During this quarter, preliminary lists of invitees were prepared with a wide group of stakeholders. The meeting was split into two different meetings. One focuses on measurement and one on reduction. An array of excellent speakers was recruited and presentations were defined. Venues were confirmed. Invitations for 24 persons for the measurement meeting (May 17-18th) were sent on March 22nd. Invitations for 56 persons for the stigma reduction meeting (May 19th) were sent on April 22nd. Travel arrangements are being made.

Two agendas have been drafted and are being widely circulated for input. PMU, WHO- Diana Weil, GFATM, USAID have provided constructive suggestions to improve the impact and ensure objectives are met. (See appendices).

7. Prepare protocol for piloting and Baseline Stigma Measurement

During this quarter a draft conceptual framework and HCW TB Stigma scale was developed by Christina Mergenthaler, Lisa Redwood, and Ellen Mitchell.

The draft scale will be pre-tested in three sites in May. Following the pre-testing, a validation protocol will be developed to explore the psychometric properties each of the components of scale. KNCV will apply for an exemption from ethical review. If approved, the scale will be applied in Q3 in a private sector sample of health workers in Lagos, as part of a project funded by a different donor (DGIS). This work will be carried out by PharmAccess.

There is also an opportunity to validate the tool in a sample of private providers in Bangladesh through a CTB sub-contract with ICDDRB.

Once a valid measurement tool is developed, it should be formally applied in several settings. Settings with a very high general population stigma level include Zimbabwe, Ukraine, Namibia, and Malawi.

<u>Nigeria</u>
Under the approved work plan, a baseline will be conducted in Nigeria. Meetings have been held with IHVN (Institute for Human Virology of Nigeria) to develop a protocol to conduct a baseline TB stigma measurement in the 12 MDR-TB facilities in Nigeria. IHVN is the PR for the GFATM grant on MDR-TB and will leverage their GFATM OR funding for the stigma intervention. A draft protocol will be developed and shared with IHVN on May 23rd following the TB stigma expert meetings in The Hague.

Administrative:

The Junior Stigma Researcher, Lisa Redwood, was hired in February and provided a much-needed productivity boost to the project and allowed the completion of major scopes of work. She had already been working as a volunteer on the project for several months, so was able to leverage her knowledge to resolve a broad array of challenges.

Technical/administrative challenges and actions to overcome them:
Further clarifications on the plan for APA 3 are needed. The project team is in discussion with PMU and USAID on next steps.

2. Year 2 activity progress

Sub-objective 1. Enabling environment								
Planned Key Activities for the Current Year	Activity #	Planned Milestones				Milestone status	Milestone met? (Met, partially, not met)	Remarks *(reason for not meeting milestone, actions to address challenges, etc.)*
		Oct-Dec 2015	Jan-Mar 2016	Apr-Jun 2016	Year end	March 2016		
Assess distribution and correlates of anticipated stigma in the general population	1.2.1	Agree on Statistical Analysis plan, compile datasets	Presentation of preliminary findings, First draft report	Final Draft Report		Preliminary results shared, refinements proposed by KNCV April 28th.	Met	Preliminary results available for sharing with Experts on May 10th
Assess the distribution and correlates of enacted stigma in health care settings	1.2.2	Agree on Analysis plan, compile datasets	Presentation of preliminary findings	Final Draft Report		Preliminary results shared, refinements proposed by KNCV April 28th	Partially met	Preliminary results available for sharing with Experts on May 3rd
Assess robustness of existing TB stigma measures	1.2.3	Compile copies of all measures/tools	Presentation of preliminary findings	Report summarizing what is known about utility, validity		Literature and dataset sent to U. Vanderbilt for analysis in March.	Partially met	Preliminary draft due May 10th for sharing with experts.
Systematic liter review Map what works	1.2.4	Finalize Protocol,	Preliminary findings, presentation	Systematic literature review		Data extracted, flow charts made,	Met	First draft of lit review expected in the first week of May.
Convene expert meetings	1.2.5		Hold meeting	Consensus recommendations,	TB stigma research agenda	Budget, invitations, agenda, venue set	Partially met	Meeting postponed until May
Prepare protocol for piloting and Baseline Stigma Measurement	1.2.6				Baseline Report on tool pilot	Validation protocol under development, Pre-test planned for first week of May.	N/A	

3. Challenge TB-supported international visits (technical and management-related trips)

#	Partner	Name of consultant	Planned quarter				Specific mission objectives	Status (cancelled, pending, completed)	Dates completed	Duration of visit (# of days)	Additional Remarks (Optional)
			Q 1	Q 2	Q 3	Q 4					
1	KNCV	Eveline Klinkenberg	Q 1				Site visit to a country that has conducted two TB prevalence surveys as part of the USAID/Gates lead Global TB prevalence survey - Cambodia	Complete	4th -11th Oct' 15	7	Finalization of the reports are currently underway
2	KNCV	Eveline Klinkenberg		Q 2			Preliminary findings were summarized and presented in Cape Town during the Union conference in Cape Town South Africa	Complete	30th Nov- 2nd Dec' 15	3	
3	KNCV	Ellen Mitchell	Q 1				Discuss stigma project with U Antwerp and KIT in Antwerp and Amsterdam	Complete	November	1	Discussions fruitful
4	KNCV	Ellen Mitchell		Q 2			Belgium	Cancelled		4	managed by phone
5	KNCV	Ellen Mitchell/ Research Assistant				Q3		Pending		7	Travel costs for 1 mission visit to the field by 2 persons- Nigeria
6	MSH	TBD	Q 1	Q 2			Conduct desk review and site visit to Ghana	Complete	October 18th – 24th '15	6	Final report received and shared with USAID.
Total number of visits conducted (cumulative for fiscal year)								4			
Total number of visits planned in approved work plan								6			
Percent of planned international consultant visits conducted								67%			

4. Financial overview

Challenge TB Quarterly financial report

Country	Measurement Stigma
Lead partner	KNCV
Other partners	MSH

Period:	Jan 2016 - March 2016

	Total
Total obligation	422,289
Total budgeted	422,289
Funds to be programmed	-
Total expenditures	143,738
Pipeline	278,551

	Total expenditures excl. ACF
Exp Jan-March 2016	17,110
Exp Oct-Dec 15	110,792
Exp July-Sept 15	
Exp April-June 15	
Average burn rate	63,951

Year 1

Partner	Approved budget	Previously reported expenditures	Reported expenditures this quarter	Accruals this quarter	Total expenditures	Remaining funds	% level of spending
KNCV	359,203	87,135	12,641	-	99,776	259,427	28%
MSH	31,415	23,657	4,469	-	28,126	3,289	90%
ACF	31,672	7,569	8,267	-	15,836	15,836	50%
TOTAL	**422,289**	**118,361**	**25,377**	**-**	**143,738**	**278,551**	**34%**

Budget category	Approved budget	Previously reported	Reported this quarter	Accruals this quarter	Total expenditures	Remaining funds	% level of spending
Salary and wages	190,453	59,414	9,431		68,845	121,607	36%
Fringe benefits	2,120	1,569	339		1,908	212	90%
Travel and transportation	61,107	6,459	-		6,459	54,648	11%
Supplies	300	-	-		-	300	0%
Contractual	21,000	-	-		-	21,000	0%
Other Direct Costs	7,700	11	-		11	7,689	0%
Indirect costs	107,938	43,339	7,341		50,680	57,258	47%
ACF	31,672	7,569	8,267		15,836	15,836	50%
Accruals	-	-	-		-	-	-
TOTAL	**422,289**	**118,361**	**25,377**	**-**	**143,738**	**278,551**	**34%**

Budget category	Approved budget	Previously reported	Reported this quarter	Accruals this quarter	Total expenditures	Remaining funds	% level of spending
1. Enabling environment	282,470	55,745	14,560		70,306	212,164	25%
12. Technical supervision	8,519	7,277	172		7,449	1,070	87%
Staffing and operations	99,629	47,770	2,378		50,147	49,481	50%
ACF	31,672	7,569	8,267		15,836	15,836	50%
Accruals	-	-	-	-	-	-	-
TOTAL	**422,289**	**118,361**	**25,377**	**-**	**143,738**	**278,551**	**34%**

Budget category	Approved budget	Previously reported	Reported this quarter	Accruals this quarter	Total expenditures	Remaining funds	% level of spending
HQ costs	334,578	115,410	25,377	-	140,787	193,791	42%
Local costs	87,711	2,951	-	-	2,951	84,760	3%
Accruals	-	-	-	-	-	-	0%
TOTAL	**422,289**	**118,361**	**25,377**	**-**	**143,738**	**278,551**	**34%**

The TB Stigma Measurement Challenge

Expert Consultation

The Hague, Netherlands

TB STIGMA MEASUREMENT

We know that perceptions about the way a person may be treated in a health care interaction strongly influence the timing, location, and quality of health seeking. We all agree that discrediting persons with TB is wrong and counterproductive Stigmatizing behavior has a negative impact on adherence and recovery.

TB STIGMA MEASUREMENT

The TB Stigma Measurement Challenge

TB STIGMA MEASUREMENT

A validated TB stigma scale that is cross-culturally robust could help to track global progress in reframing TB and could assist to identify effective interventions to reduce shame, discrimination and fear of mistreatment.

TB STIGMA MEASUREMENT

However, there are many questions as to whether such a measure is possible. TB stigma is not a universal social fact (as it is often imagined) but rather a culturally constructed and potentially dynamic construct. Indeed some studies suggest that an identical behavior can be experienced as more or less stigmatizing depending on the characteristics of the person . So TB stigma may not be measurable with a uniform questionnaire. It may be yet another instance where an intersectional approach to multiple forms of difference (prejudice based upon race, gender, class, co-morbidities, sexualities) may be required.

KNCV Tuberculosis Foundation, together with academic and policy partners, will

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CHALLENGE TB

convene an expert consultation to unpack TB stigma measurement scales. The consultation will present preliminary results of new studies, and serve as a technical forum to debate current and future tools.

The objectives of the meeting are to

1) *critically review the evidence for existing scales and methods and make recommendations for best practices*
2) *identify research gaps in TB stigma measurements and propose a research agenda*

The agenda is under development, but the main questions to be tackled include:

What do TB stigma scales actually measure?

We recognize that many TB patients are managing multiple identities that are stigmatized. This makes measurement additionally challenging. By asking vague close-ended questions about discrimination, one risks conflating many different types of prejudice.
We know that when providers lack cultural competence with a wide array of TB patient groups their contact investigations are of lower quality and effectiveness. We observe this with treatment adherence and outcomes as well.

- *Is TB stigma indivisible from HIV stigma?*
- *How do TB stigmas relate to stigmas of poverty, incarceration and/or substance use?*
- *What do the validation studies tell us about the utility of TB stigma scales?*
- *Are TB stigmas essentially compound stigmas?*

What does the presence of anticipated, internalized, and enacted TB stigma mean for behavior?

Even when there is agreement on TB stigma as a concept, there is not always a linear or predictable consequence on behavior. Indeed in at least some TB stigma studies shame associated with TB actually increased timeliness of case seeking.

- *Do higher rates of anticipated TB stigma in the general population correlate with lower health care seeking for TB symptoms?*
- *Do higher rates of enacted TB stigma in health care settings lead to reduced TB*

screening or lower rates of TB testing?

- *How do we understand settings with high measured levels of TB stigma but also high levels of TB care seeking, treatment adherence, good outcomes?*

How important is measuring TB stigmas?

Given the measurement challenges, is it really TB stigma we want to track and measure? Or are we better off tracking something easier like the cultural competence of TB health care providers to work effectively with stigmatized communities?

- *How important is reducing TB stigma for TB patients? Is it the top priority?*

Program

The 2-day program is under development. Current plans include: seven scientific presentations of new research on TB stigma measurement, small technical discussions of key measurement questions, debates, and group work. We are exploring the potential for proceedings to form a special issue of a peer review journal.

The expected deliverables for the meeting include:

1. A consensus statement on TB stigma measurement practices for specific populations and types of stigma
2. A consensus research agenda

Next steps?

Following the meeting, easy to follow guidance should be generated and disseminated to partners to ensure TB stigma measurement is robust and informative. Remaining scientific questions should be answered through appropriately designed studies and promising tools should be piloted.

Logistics

The meeting will take place over two days (May 17th and 18th) in at KNCV TB Foundation offices. Benoordenhoutseweg 46 2596 BC The Hague, Netherlands

Zero draft for comments

The TB Stigma Measurement Challenge

Expert Consultation

May 17-18th, 2016

24 measurement people

A small technical expert meeting at KNCV to debate and formulate strategies to address the TB stigma measurement challenges for anticipated, internalized, enacted stigma.

Meeting Objectives

1. We will define a TB stigma measurement research agenda,
2. make concrete recommendations on how to improve existing measurement tools
3. Identify how and where to pilot revised tools.

Day 1

Q	WHO	T
the Quest for Quantification of Stigma-	WHO- Ernesto Jaramillo	
Building Stigma Indicators- What do want to measure? What changes can we expect?	Charlotte Colvin/Susan Bergston	
What is TB stigma? Typologies, controversies, debates and challenges	Kate Macintyre	
Unpacking TB Stigma using Scales and Surveys		
Overview of the TB stigma scale landscape: What do the validation studies tell us about the utility of TB stigma scales?	Aaron Kipp U. Vanderbilt/ KNCV	
Do Secrets Imply Stigma?: Is hypothetical willingness to disclosure TB disease a valid proxy for anticipated TB stigma in the general population?	Ellen Mitchell/Charlotte Colvin	
Validation of a TB stigma scale for health care workers in South Africa- Capturing the duality of HCW in South Africa	Edwin Wouters U. Antwerp	
Discussion of methodological issues in application of TB stigma scales – sizing, sampling, bias and data collection	Wim van Brakkel	

Day 2

Q	WHO	T
Traversing the TB Stigma Landscape		
Stigma Hotspots? Mapping TB stigma among and within 39 countries	KIT/KNCV	
Untangling the Correlates of TB Stigma -		
Are there socio-demographic correlates of TB disease disclosure attitudes in the general population? Data from 17 countries	Mirjam Bakker (KIT)	
Who sees what? Which individual, organizational, and structural factors influence the perception of discrimination against PLHIV within health care settings in Kenya, Namibia, Tanzania, and Rwanda	Mirjam Bakker	
Are TB stigmas compound stigmas? How do TB disease disclosure attitudes relate to stigmas of poverty, incarceration, substance use, and HIV across 39 countries?	Ente Rood (KIT)/	
Not your grandfather's TB stigma: -Is anticipated TB stigma dynamic over time and how should this dynamism be understood?	Christina Mergenthaler	
How do the rise of multi-drug resistance and HIV shape current constructions of TB stigma and how does this impact our stigma measurement challenge?	Amrita Daftary U. Toronto/ICAP/UCT	
METHDOLOGY BREAKOUT SESSIONS • MEASUREMENT IN HEALTH CARE WORKERS/ HEALTH CARE FACILITIES • GENERAL POPULATION • TB RISK GROUPS		
CONSENSUS ON TB STIGMA RESEARCH AGENDA	Annelies van Rie	

Dr Suvanand ***Sahu***
Deputy Executive Secretary
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Appendix 2 – TB stigma reduction meeting draft agenda

GETTING TO ZERO TB STIGMA

ZERO DISCRIMINATION:

Are TB stigmas susceptible to intervention and how do we get there?

May 19th, 2016

9:00-15:00

Humanity House, The Hague

The new global END TB strategy has a bold vision to end suffering from TB, but no clear definition of "suffering" or indicators to measure it. We know that catastrophic costs, death and disability are forms of suffering that will be measured, but the issue of social exclusions and violation of rights is less likely to be captured and thus more prone to be forgotten.

An expert meeting on TB stigma measurement is to be held in the Hague on the 17th and 18th But once TB stigma can be reliably measured, our lack of understanding of effective TB stigma reduction strategies is the next hurdle. The draft Global Fund Strategic Plan 2017-2022 promises a shift on stigma "moving from rhetoric to investing" (p.21). This sounds promising, but when these resources become available will we know how reduce TB stigma? Is the TB stigma reduction toolbox ready with evidence-based solutions?

We know from the HIV world that HIV stigma has evolved over time as a consequence of policy, treatment and societal shifts. We are less sure of how TB stigmas are evolving over time. TB stigma predates HIV stigma by milennia but most of what we know is from localized ethnographic work that (while rich), offers few big policy directions or change theories to test.

We plan a one day meeting at the Humanity House to bring stakeholders together to engage with the available evidence. Bringing policy makers, technical partners, donors, and

academics together in The Hague we will review new studies. The goal of the meeting is to leverage the expertise of global stigma experts to identify testable interventions for TB stigma reduction. We will seek to identify contexts and approaches to be tested, and to identify partners who can work together to implement (and measure) TB stigma reduction efforts..

Among the key questions to explore at the TB Stigma Reduction meeting are:

- *Are TB stigmas dynamic over time and how can these dynamics be explained?*
  - *What (if anything) makes TB stigma uniquely challenging? Does the airborne transmission issue serve to justify social distancing, separation, and exclusion?*
  - *What can be learned from other anti-stigma efforts in the mental health, disability, substance use, HIV, ebola and leprosy fields?*
- *What are the evidence-based approaches to reduce TB stigmas?*
  - *Do rights based and patient-centered approaches lead to empowerment and reductions in internalized TB stigma?*
  - *Is knowledge really power? Does education hold the key to reducing TB stigma? Is correct knowledge of TB transmission or curability associated with lower TB stigma?*
  - *Does a private sector (consumer satisfaction) focus reduce stigma?*
- *How do health care workers fit into the stigma equation? They are often both stigmatized by their peers for their TB work and yet some internalize and reproduce TB stigma in the workplace? What is effective to both shield them from and engage them on TB stigma?*
- *Does TB stigma reduction require an intersectional effort –with distinct strategies for different ages, ethnicities, genders, and races?*
- *Does service integration affect TB stigma positively or negatively?*
- *Does community engagement reduce or increase stigmatization?*
- *What is the economic cost of TB stigma? Can it be quantified?*

The meeting will take place at The Humanity House, and ideal venue because of its focus on inclusions/exclusions, rights, and struggles against “inhumanities” of all kinds.

https://www.humanityhouse.org/en/all-about-inhumanity/storywall/

The meeting will also include an opportunity to visit the museum and to participate in a simulated migration journey involving stigmatization. The agenda includes unpublished studies by Royal Tropical Institute, KNCV, University of Antwerp, and Netherlands Leprosy Relief. This event is linked to (and builds upon) a consultation on TB stigma measurement held at KNCV on May 17th and 18th.

The agenda is still under development and stakeholders are encouraged to share ideas with KNCV senior epidemiologist Ellen Mitchell ellen.mitchell@kncvtbc.org to help shape the meeting. To RSVP before May 5th and/or for more information on logistics, travel, dietary needs or accomodations please contact Marianne Weiser marianne.weiser@kncvtbc.org .

GETTING TO ZERO TB STIGMA

Effective TB Stigma Reduction

Are TB stigmas susceptible to intervention?

What works for whom?

Thursday, May 19th, 2016

Facilitator: Kate Macintyre

Illustrative agenda - DRAFT

Q	WHO	T
Getting to Zero	ty van Weezenbeek	
The global momentum to tackle TB stigma – the investment case for TB stigma reduction	BD-WHO/UNAIDS	
Synthesizing the TB stigma reduction literature		
What are the evidence-based approaches to reduce anticipated TB stigma in the general population? What are the evidence-based approaches to reduce internalized and enacted TB stigma?	U. Antwerp/ KNCV Nina Sommerland	
Is knowledge really power? Can educational interventions work to reduce TB stigma?	KIT/ KNCV	
Creating Safe Spaces for TB Patients and Health Care Workers		
The 2016 'Unmask Stigma' Campaign	TB Proof (NOT CONFIRMED)	
Health Care Workers as Change Agents - Implementing interventions to reduce TB/HIV stigma in health care settings in South Africa	U. Antwerp	
Don't Reinvent the Wheel: Synergies and Lessons Learned for Reducing Stigma		
What works to reduce HIV stigma?	Anne Stangl ICRW	
What works to reduce Leprosy stigma? Results of a randomized control trial in Indonesia	Wim van Brakel Netherlands Leprosy Relief (NLR)	

Reducing stigma by portraying mental illness and drug addiction as treatable health conditions: Does it work?	TBD
Who reports discrimination in health care facilities? Correlates of health care worker willingness to report workplace discrimination against PLHIV	KIT/ KNCV
Stigma reduction panel discussion– learning from PWUD, MSM, Trans, informal migrant social movements	
TB Stigma Reduction – Presenting a Research & Policy Agenda	Annelies Van Rie
Where do we go from here? Building TB stigma reduction into national TB strategic plans and grant mechanisms	USAID/GFATM

End formal program by Thursday, 15:00

Tour of the Humanity House Museum

Interactive Migration simulation

Potential Side meetings: 15:30-17:00

Curriculum development **15:30-16:30**	**A 1 hr meeting for the team who will be drafting the curriculum on reducing TB stigma –**
CT measurement & indicators meeting **16:00-17:00**	**A 1 hr mtg for teamwho will be working on operational research in APA 3 –MEASUREMENT**
Co-authors meeting **16:30-17:30**	**a 1 hr mtg with co authors of the various studies to share feedback and set timelines for manuscript submission.**